

Testimony of Carol Levine United Hospital Fund

Good morning. My name is Carol Levine and I am Director of the Families and Health Care Project at the United Hospital Fund in New York City. Since its founding in 1879, the United Hospital Fund has been devoted to shaping positive change in health care delivery and financing. The Fund works through philanthropy, research, and program and educational development.

Thank you very much for inviting me to testify before you today on the important issues facing family caregivers. In convening this hearing, the U.S. Senate Select Committee on Aging has taken an important step in increasing the awareness of policy makers, health care professionals, and the general public about the critical role of family caregivers in the well-being of our nation's elderly people, and those who are chronically ill or seriously disabled, whatever their age. I am delighted to be able to introduce at this hearing a new special report from the United Hospital Fund called "Rough Crossings: Family Caregivers' Odysseys through the Health Care System." The entire report has been provided to supplement my testimony.

The Importance of Transitions

The report focuses on transitions -- patient moves to and from hospitals, nursing homes, or rehabilitation units -- and how these transitions affect family caregivers. The main source of information was a series of six focus groups held in New York City with 56 experienced family caregivers. The caregivers were a very diverse group, including men as well as women, people with many different ethnic backgrounds, educational levels, family incomes, and ages. The caregivers ranged in age from 20 to 70, with the majority in their 30s and 40s. Many held jobs, although some had been forced to leave employment to take care of their family member. The care recipients were mostly women between the ages of 60 and 80 with multiple serious health conditions.

At the beginning of the hearing you saw and heard on video three of these caregivers talk about their lack of preparation for the task, their anxiety about taking proper care of their loved one, and the isolation that comes with long-term caregiving.

* "The first night she came home from the hospital we went to bed and I found that she was incontinent and that her bandages were oozing. No one had told me what to expect. I didn't know who to be angry at or who to call to help me take care of her."-- A husband whose 71-year-old wife has multiple sclerosis and had extensive surgery for a bone infection

"I was terrified. My generation doesn't know about computers. They put in a feeding tube and showed me --- 1,2,3 -- how to use it. But I was expected to be responsible for it at home." -- A wife whose elderly husband has had several strokes.

Here is another voice, which is not on the video you saw.

* "I had to fight through layers of bureaucracy for ten days to get a dangerously unstable hospital bed replaced at home. Then when the bed arrived -- without notice. in the evening when there was no one to help me move him -- it turned out to be the wrong bed."-- A wife who takes care of her 70-year-old husband left quadriplegic and brain-damaged after an automobile accident 8 1/2 years ago.

The last voice is mine. Like the caregivers in our focus groups, I am one of the more than 25 million

other family caregivers who are struggling with the fragmented, inflexible, and increasingly complicated collection of institutions and agencies called "the health care system."

I joined the United Hospital Fund in October 1996 to create the Families and Health Care Project after a long career in health policy and medical ethics, which included being awarded a MacArthur Fellowship for my work in AIDS policy. Yet nothing in my professional background, or my experience as a mother of three children, had prepared me to be the caregiver for a severely disabled, brain-injured husband.

Why Systems Must Change

Professionals call us "informal" caregivers to distinguish us from paid workers, implying that there is something casual and nonessential about our care. Because we love the people we take care of, we do not ordinarily see ourselves as anything but spouse, child, sibling, partner, friend. In fact, we take care of the basic health, social, and emotional needs of people who are disabled or chronically or terminally ill, and who are only sporadically hospitalized. Sometimes we have to make our homes into mini-hospitals, crowded with high-tech equipment we operate and monitor. In the past few years the health care system has changed dramatically. Cost-containment has shifted responsibilities to patients and families in unprecedented ways. This hearing is an important step in looking at that impact systemically.

Despite the near-universality of caregivers' experiences, our stories will remain just individual anecdotes that evoke sympathy, shock, or avoidance until the health care system begins to change. And it is the system that must change. This is a potentially revolutionary idea.

Today, the formal health care system expects family caregivers to change, to accept its irrational and often contradictory array of rules and regulations, the pervasive lack of communication and information, and inadequate training and follow-up. Even much of the family caregiving self-help literature focuses on "coping" - learning how to live with an intolerable situation by changing one's own attitude and expectations. Coping skills are important, but there are limits to what even the most successful copers can sustain. Martyrdom-or indeed heroism--is not an ethical or practical standard for public policy or health care practice.

The devastating results of the health care system's lack of attention to family caregivers can be seen every day. Middle-class families who thought they had comprehensive health insurance are being impoverished by caregiving, since much of what they need at home is not deemed "medically necessary" by insurers or falls under the unreimbursable category of "custodial care." There are well-documented mental and physical health risks to caregivers. Employers face productivity loss and absenteeism when valuable workers juggle the competing demands of job and caregiving. Without support and guidance, families can be irreparably torn by dissension. Divorce is not uncommon; suicide not unheard-of. Other family members, children in particular, may be denied the care and attention of the caregiver preoccupied with the ill person.

What can be done to encourage and require the health care system to change? There is no single solution, no law or regulation that will by itself make a difference. In a long-term agenda, high priority should be given to building an understanding of the needs of family caregivers into medical, nursing, and social work education. But several important steps can be taken now.

United Hospital Fund Initiatives

* The United Hospital Fund has already added family caregiving to its philanthropic and research agenda. The very existence of a project like mine in an organization with "hospital" as its middle name

is evidence of the growing awareness that it is in institutions' economic interests as well as humanitarian missions to understand and address the needs of family caregivers. Studies show that even modest, targeted attention to family caregivers can prevent or delay costly hospital readmissions or nursing home placement.

*The Fund commissioned Peter Arno to develop the first systematic estimate of the economic value of informal caregiving. He presented the sobering results to you today.

* The Families and Health Care Project prepared a series of guiding principles to promote effective partnerships between health care professionals and family caregivers. These too are included in the special report, "Rough Crossings."

* The Fund has embarked on an ambitious three-year \$1.3 million grant initiative to change the way hospitals work with family caregivers and other health care providers. In its first phase, 16 New York City hospitals were awarded planning grants to gather and analyze information about family caregivers. Dr. Mary Mittelman, my co-panelist, is one of the grantees. In February we will award about six two-year grants of \$150,000 to \$200,000 each to test model interventions to change hospital practice and procedures.

* In the coming year we will be embarking on other activities that build on our initial work, and we will continue to join in collaborative efforts with the many active consumer and health care groups that are already dedicated to improving services for family caregivers.

Recommendations

Of course we cannot meet this challenge alone. For our colleagues in health care and for policy makers at all levels we offer several suggestions for program review and development. The key elements are family caregiver involvement, information and communication, training and education, and a variety of support services. Specifically,

** Hospital staff should make discharge planning and transitions between home and hospital a process, not a last-minute, one-time event. "Rough Crossings" contains not only experiences of caregivers, but also the perspectives of hospital staff as well. Health care professionals confirmed what family caregivers stressed--that discharge planning, as currently practiced, often fails to meet the needs of family caregivers. Most discharge planning focuses on who is paying for what, leaving the family caregiver to sort out an often confusing array of medications, machines, and instructions. Many caregivers felt abandoned at a critical time. If managed care is to fulfill its promise, it must truly be care management, not just cost containment.*

Our report contains a series of outlines called "Covering the Basics for Family Caregivers." They are lists of items to discuss when planning for different situations, when the patient is in the hospital, for example, or prior to discharge, or when the patient is terminally ill. We suggest that these outlines can be practical guides for health care providers and family caregivers to start an ongoing discussion. For these or any other discussion aids to be effective, however, there must be appropriate services and training in place. Thus, our next recommendation:

**A high priority should be given to developing a broader array of programs that support family caregivers. There are not enough counseling, support, and respite services for the many different types of caregivers and their special needs. Some excellent programs exist but many caregivers do not know what is available or where to look for help. None of the caregivers in our focus groups reported a*

professional referral to a community-based agency for further assistance, counseling, or information. Some eventually found such an organization on their own.

** Health care professionals should be assertive advocates for family caregivers.* As one of our basic principles states, professionals have responsibilities toward family caregivers who provide, monitor, and manage their patients' care at home. Resourceful and willing though they may be, family caregivers need advice, expertise, and especially advocacy from those who know the ins and outs of health care bureaucracies.

Insurers and their subcontractors should be held to a high standard of performance and accountability. In a hospital my husband's unsafe bed would have been replaced immediately, if for no other reason than concerns about liability. Institutions have clout; individual family caregivers have little. Managed care companies and insurers frequently set up barriers to immediate service and limit choices of equipment vendors and other service providers. Family caregivers need a simple, systematic way to report poor service and bureaucratic hassles; and they are entitled to a timely response.

**Insurers and public program administrators should recognize that communicating with family caregivers is essential to quality patient care.* Even the most dedicated clinicians cannot spend the necessary time communicating with family caregivers unless they are reimbursed adequately. The simplest intervention -- listening to family caregivers and assisting them to do the hard job they have lovingly taken on -- may be the most critical.

Finally, what can policy makers, especially at the federal level, do?

I believe that the single most important change in federal and state policy is an explicit recognition of the critical role of all family caregivers in the health care system, not just those whose care recipients receive services from Medicaid or Medicare. This implies a recognition of the links between the "public" and "private" sectors. Public policy decisions on programs like Medicare and Medicaid set the basic framework for the private sector in terms of service development and availability, criteria of "medical need," wages in the labor market, and so on. To look at it positively, an emphasis on serving family caregivers in the public sector will have an important carryover into the private sector where managed care companies increasingly determine benefits. Private foundations have an important role as well in supporting innovation, evaluating new programs, and stimulating research.

A Family Impact Statement

Furthermore, health and social service policy decision making should include a family focus. I suggest that a "family impact statement" should accompany major policy decisions. We expect the same for the environment and for paper reduction. Aren't the people who are the bedrock of the health care system equally important?

One specific example is the hospice benefit under Medicare. Hospice is one service is based on the importance of the family unit and offers ongoing support as well as a bereavement and follow-up service. But hospice also relies heavily -- more heavily than most people realize -- on the direct care provided by family members. Efforts to contain hospice costs have had a chilling effect on admission to hospice. This in turn has a serious impact on family members who have been caring for a seriously ill loved one for long periods and who look to hospice for assistance in the final months of intense caregiving. Here is one program where a "family impact" statement would help define the context in which efforts at containing costs and eliminating fraud take place.

Policy makers at all levels have long been ambivalent about family caregivers. Yes, they say, they are important, and we certainly don't want them to give up because that will add to the public burden. But no, they hasten to add, we don't want to do too much for them because of the "woodwork" effect. The "woodwork" effect suggests that once given a chance for some relief, family caregivers would come out of the "woodwork," like so many unwanted insects, with greedy appetites for resources. Speaking for myself, I am not part of the woodwork. I am part of the foundation on which our health care system rests. And if the foundation collapses, the entire structure is endangered.

What do family caregivers themselves say they want? In the twelve hours of caregiver conversations in our focus groups, and in countless other conversations: this is what I have heard again and again: "Someone to talk to who understands what I'm going through." "Someone to call when I have questions." "Technical training that recognizes my emotional involvement with the patient." "A day off." "A kind word from a doctor or nurse or social worker."

These are hardly overwhelming demands. Meeting such modest requests would be a strong beginning to humanizing our health care system for patients, families, and professionals alike.

Thank you again for the opportunity to speak to you today. I will be happy to answer any questions.